



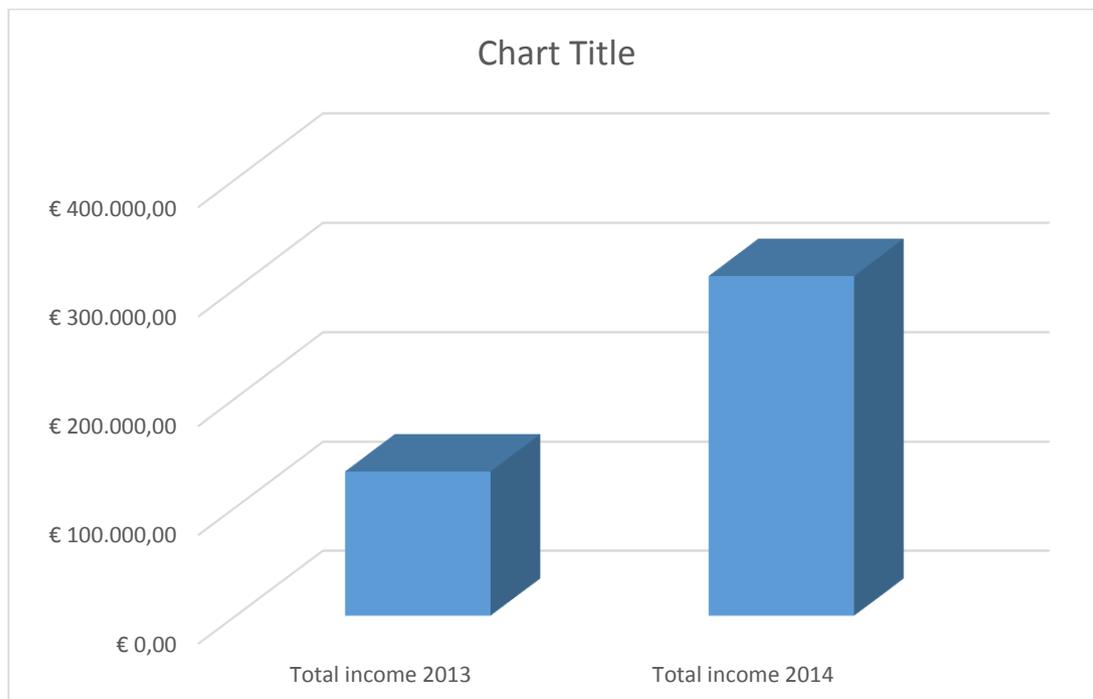
ECPC Financial Report - 2014 in figures -

The financial report has been prepared taking into account the costs registered in the financial statement of ECPC.

The total income in 2014 **increased by 154%** in comparison with the previous year, reaching a total of **€ 204.260**. This was due to the continued efforts of rebuilding the positive reputation of ECPC and reinstating the trust of our sustaining partners by proposing innovative projects. Compared with last year, the organisation has diversified the partners financially supporting the projects of ECPC (eg. ECPC started a solid collaboration with new partners such as MSD and Celgene).

Income 2013/2014

Total income 2013	€ 132.608,27
Total income 2014	€ 311.214,17
Increase of income by 135%	€ 178.605,90





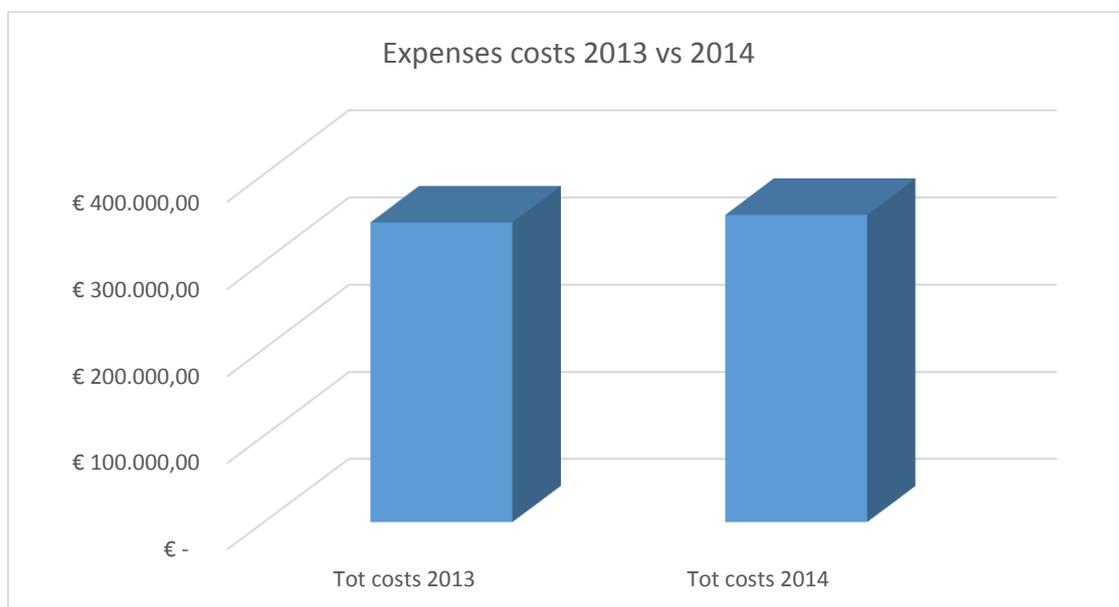
Professionalisation of the office

The total costs have registered a marginal increase of 2.5%. However, this is a planned development as **the organization currently employs 4 full – time staff**. Previously, only 2 full-time staff were employed, while other collaborators were employed with part-time/student/volunteer contracts. The shift in the number of staff increased expenditure but ensured a professional office that is developing more and more projects – both funded by the EU and industry, thus increasing income.

It is also worth noting that the balance of professional efficiency vs payroll amount as ECPC salaries are in the median of salaries paid for similar positions in NGOs in Belgium.

Costs 2013/2014

Total costs 2013	€ 344.626,44
Total costs 2014	€ 353.295,17
Increase of costs 2,5%	€ 8.668,73





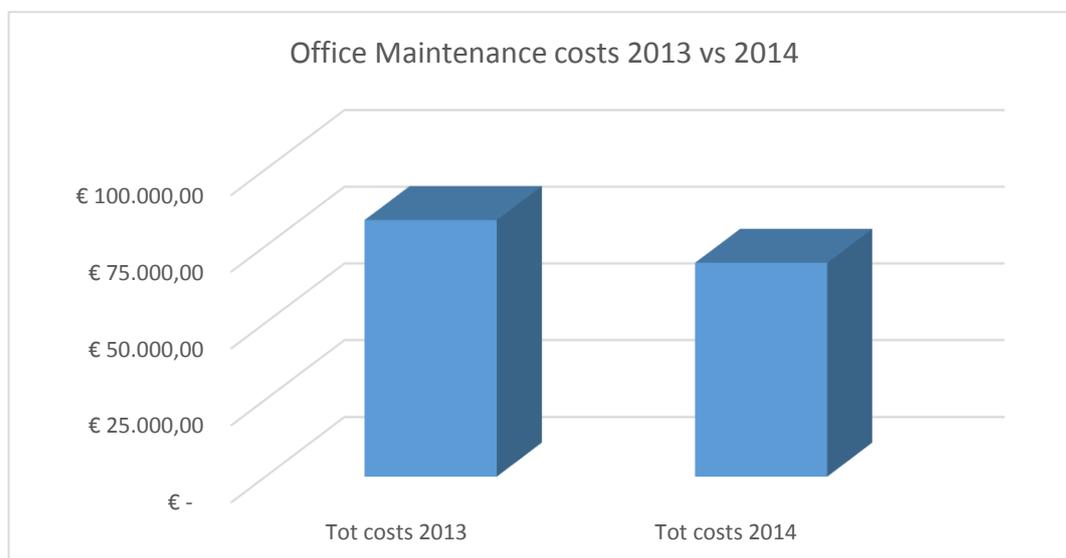
Decrease of Office Maintenance Costs

While the personnel costs increased, for the reasons explained above, the Office Maintenance Costs (*rent, internet, phone, stationary, water, etc.*) decreased from € 83.493,22 to € 69.562,89 thus registering a decrease of 16.7%.

One of the explanations for the decrease of the maintenance costs is the fact that the office is now shared with another organisation, RADIORG, dealing with rare diseases, that pays a rent of 8.400 euro/year (700 euro/month).

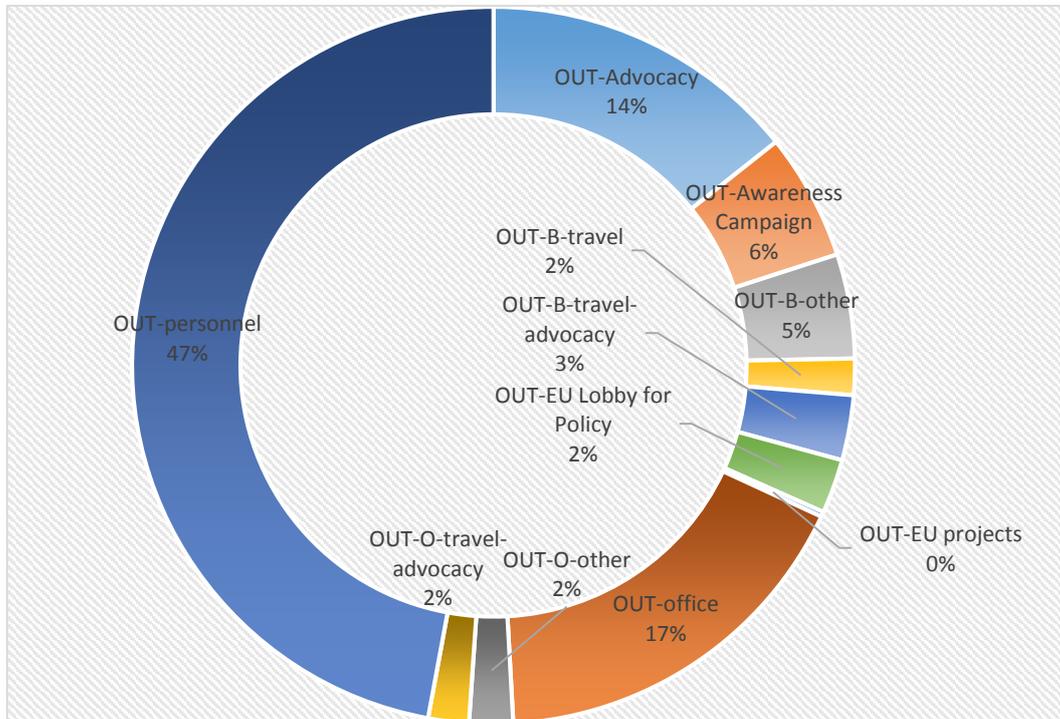
Office Maintenance Costs 2013/2014

Total costs 2013	€ 83.493,22
Total costs 2014	€ 69.562,89
Decrease of costs 16,7 %	€ (13.930,33)





Small costs for Policy and Advocacy Activities vs big achievements on major topics



Policy and advocacy initiatives take an important part of ECPC resources. Yet, with the little financial resources allocated to policy and advocacy, ECPC succeeded, between June 2014 and June 2015, to consolidate its position within the European public health policy arena. Below ECPC presents a list of the most important policy initiatives undertaken within last year, with a brief description of the initiatives' objectives and outcomes.

ECPC policy initiatives

[First World Pancreatic Day, 13th November 2014, Brussels](#)

ECPC joined Pancreatic Cancer Patient organizations across the world to organise and celebrate on November the 13th the first World Pancreatic Cancer Day. After more than 6 months of preparation, a series of events and initiatives within the European Parliament marked the WPCD2014, including:

- An awareness campaign inside the Parliament, ran by ECPC;
- The drafting of the political [Call-to Action](#) led by Members of the European Parliament [Dr Philippe Juvin](#) (EPP, France), [Philippe De Backer](#) (ALDE, Belgium), [Françoise Grossetête](#) (EPP, France) and [Daciana Sârbu](#) (S&D, Romania);
- The launch of the **European Platform on Pancreatic Cancer** which gathers leading experts involved in pancreatic cancer, in the field of academia, research, patient organizations, policy-makers and industry.

[Immuno-Oncology Policy Action Framework, 19th November 2015, Brussels](#)

On the 19th November 2014, the European Cancer Patient Coalition (ECPC), together with Philippe de Backer, ALDE MEP and Cristian Silviu Busoi, EPP MEP, launched two important new documents at the European Parliament (**Immuno-oncology: a policy action framework** and **What is immuno-oncology: a guide for patients**). These documents are designed to improve the understanding of policymakers and patients of immuno-oncology therapies and the role that they may play in the future care of cancer patients.

[Europe of Disparities, 27st January 2015](#)

On the [27th of January](#), ECPC co-organised with [MEP Elisabetta Gardini](#) (Head of the Italian EPP Delegation) an event at the European Parliament, in order to raise awareness on the inequalities in cancer care existing in Europe. “Europe of Disparities” is the first of a series of events organised by ECPC within the European Parliament on inequalities in cancer care. The second event of the Europe of Disparities initiative will take place in autumn 2015. Here, the ECPC position paper on inequalities in cancer care will be presented.

World Cancer Day 2015, 4th February 2015, Brussels (Belgium)

- **World Cancer Day press conference at the European Parliament**
Thanks to the support of [MEP Elisabetta Gardini](#), ECPC contributed to the launch of the 4th February Declaration which reaffirms the principles of the European [Bill of Cancer Patients' Rights](#) and recommends 4 main pillars for action to the European Parliament and the Commission. The document, supported by 160 MEPs was launched during a multi-party press conference.
- **Meeting with the Chair of ENVI Committee, Giovanni La Via**

Before the press conference, ECPC President Francesco De Lorenzo and ECPC Vice President Kathi Apostolidis met MEP Giovanni La Via, chair of the ENVI Committee.

- **Meeting with Commissioner Andriukaitis**

Due to the success of the Declaration, ECPC President Prof De Lorenzo and ECPC Vice President Kathi Apostolidis met Vytenis Andriukaitis, European Commissioner for Health and Food Security.

Get Tested campaign - [Metastatic colorectal cancer and the use of RAS biomarker testing, Brussels \(Belgium\), 24th March 2015](#)

The Get Tested campaign aims to raise awareness and understanding of the importance of RAS biomarker testing in patients who are newly diagnosed with metastatic colorectal cancer (mCRC) and to encourage them to discuss testing with their doctor.

The Campaign also presented a White Paper to Members of the European Parliament and European Commission representatives calling for improved access to testing for patients newly diagnosed with metastatic colorectal cancer (mCRC) and for the routine use of RAS biomarker testing in establishing a personalized cancer care plan.

[Survey on patients' awareness of medical nutrition in cancer, February-May 2015](#)

Physicians and patients alike often neglect a fundamental aspect of cancer treatment: nutrition. ECPC launched a new project to discover what patients know about medical nutrition. The survey, developed in partnership with researchers from the University of Rome "La Sapienza", has been answered more than 660 times. Preliminary results of the survey will be presented at the AGM 2015.

- **Participation to international conferences**

[European Society of Medical Oncology Congress, Madrid \(Spain\) 26-29 September 2014](#)

(De Lorenzo, Apostolidis, Pelouchova, Militaru)

The Patient Advocacy Track provided European patient organisations, oncologists and bodies involved in patient care with an excellent networking opportunity – giving participants the possibility to discuss vital issues and challenges faced by cancer patients. ECPC, as a Member of the [ESMO Patient Working Group](#), actively participated into the definition of the ESMO2014 Patient Track, which took place on the 27th and 28th September 2014.

[European Health Forum Gastein, Gastein \(Austria\), 1-3 October 2014](#)

(Florindi)

The EHFG is the most important high-level public health forum in Europe, bringing together experts from across Europe to discuss the future of health, including cancer. Francesco Florindi was awarded with a scholarship to attend the meeting.

[Future of Healthcare, Brussels \(Belgium\), 18th November 2014](#)

(DeLorenzo)

De Lorenzo has been invited to co-chair a roundtable discussion on "Next generation in health accreditation" organised within the Roundtable on the Future of Healthcare, hosted by [MEP Christel Schaldemose](#) and supported by [Sustania](#) and [DNV-GL](#). The meeting aimed at inspiring smarter, safer and more sustainable healthcare systems that put the person in the centre of care.

[EU clinical trials portal and Union database, London \(UK\), 9th December 2014](#)

(Apostolidis, Swierzewski)

ECPC Representatives to the EMA Kathi Apostolidis and Rafal Swierzewski will take part to the stakeholders meeting organised by the Agency on the new EU clinical trials portal. According to the recently approved [Clinical Trials Regulation](#), the portal has to be created as a centralised hub for the registration of all European clinical trials. This represents a legal requirement of the new Regulation. K. Christoforidi attended the annual training offered by EMA to members of the PCWP, in order to increase our in-house knowledge and understanding of the activities of the EMA and PCWP.

[Cancer Drug Development Forum 8th Alpine Meeting, Innsbruck \(Austria\), 2-4 March 2015](#)

(F. de Lorenzo, F. Florindi)

CDDF pulls together patients, regulators, academia and industry in a unique forum focused on the development of innovative treatments for cancer patients. In the presence of EMA and FDA officials and representatives from the most important European HTAs, Prof De Lorenzo expressed the need to

make innovative cancer drugs more quickly available to patients. To do this, he affirmed that it is necessary to harmonise the HTA evaluation at European level, and move forward with the positive example of adaptive licencing.

[European Association of Hospital Pharmacists, Annual Congress, Hamburg, 24-27 March 2015](#)

(F. de Lorenzo)

ECPC President Francesco de Lorenzo has been invited as a speaker to the [Annual Congress of the European Association of Hospital Pharmacists - EAHP](#). Prof De Lorenzo met EAHP President Dr Frontini to discuss a range of issues, including addressing inequalities in healthcare provision across Europe. On the 26th March, Prof De Lorenzo delivered a speech on the patients' perspective during the "Stakeholder discussion on responding to the information challenge posed by medicines shortages".

[Bucharest Forum Healthcare, Bucharest \(Romania\), 27th March 2015](#)

(F. de Lorenzo)

ECPC President Francesco De Lorenzo has been invited to participate as panellist to the [Bucharest Forum Healthcare](#) organised by Aspen Institute Romania.

Relationship with the European Commission and the European Medicines Agency

○ [European Commission's Expert Group on Cancer Control](#)

The expert group will assist with drawing up legal instruments, policy documents, guidelines and recommendations on cancer control, at the request of the Commission. F. de Lorenzo and K. Apostolidis represent ECPC within the Expert Group. The Expert Group has been called to work on opinions related to:

- Rare Cancers
- Palliative care

○ [Joint Action on Cancer Control - CanCon](#)

○ The European Guide on Quality Improvement in Comprehensive Cancer Control – CanCon is the second Joint Action launched by the European Commission to harmonise the way EU Member States fight cancer.

○ CanCon aims to contribute in different ways to reducing the cancer burden in the EU. **The main product of CanCon will be the European Guide on Quality Improvement in Comprehensive Cancer Control.** Francesco De Lorenzo and Kathi Apostolidis represent ECPC within CanCon, particularly contributing to:

- WP4 Guide production
- WP5 Member State Platform
- WP6 Integrated Cancer Care
- WP8 Survivorship and Rehabilitation
- WP9 Screening

F. De Lorenzo, K. Apostolidis and F. Florindi participated to several CanCon meetings, including:

- **First CanCon Stakeholders Forum, Brussels, May 2014;**
- **Second CanCon Stakeholders Forum, Brussels, May 2015;**
- **WP8 Expert Group meetings.**

Transcan-2

ECPC has been invited to participate in the Scientific Advisory Board of **TRANSCAN-2** research EU funded project, where it will be represented by its **Vice-President, Kathi Apostolidis**.

The objective of TRANSCAN-2 is to contribute to the building of the European Research Area through the coordination of national and regional translational cancer research funding organisations' activities, aiming at the integration of basic, clinical and epidemiological cancer research and facilitation of transnational cancer funding in Europe.

TRANSCAN-2 is the continuation of the **ERA-NET on Translational Cancer Research (TRANSCAN)**, an initiative funded by the European Commission's ERA-NET scheme under the EU Framework Programme for Research and Innovation Horizon 2020 Societal Challenge: Health, Demographic Change and Wellbeing.

- **Lobbying on European legislation**
- **General Data Protection Regulation**

After having supported ESMO Position Paper on the Regulation, ECPC lobbied the Council of the European Union during the Italian Presidency for the introduction of amendments that would ensure the survival of cancer registries, pivotal for the creation of historical and perspective epidemiological studies on cancer. In February, F. de Lorenzo met with Italian Undersecretary of State for Justice Mr Ferri to advocate the case of cancer patients on the matter.

- **Cross Border Healthcare Directive**

F. de Lorenzo and F. Florindi carefully followed the process of implementation of the Directive, in particular requesting information to the European Commission on the statutes of harmonisation of the Directive. In April 2015 DG SANTE, following the successful meeting between ECPC and Commissioner Andriukaitis in February, welcomed ECPC comments and contribution to the production of the implementation report.

Annex 1 - Profit and loss statement 2014